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COMMENTARY

Participation of children born less than 30 weeks' gestation: A time for action

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Infants born very preterm (VPTs) present as one of the most vulnerable populations globally. Although medical advancements have improved survival rates and reduced morbidities, as birthweight and gestational age decrease there continues to be increased risk of long-term medical and functional disabilities.¹ A significant number of VPTs also receive a diagnosis such as cerebral palsy, autism, or developmental coordination disorder.² This further increases the heterogeneity of the group and their pathways through health services. Many therefore receive services that focus on a secondary diagnosis, with little attention placed on the unique health condition of very preterm birth.

Once medically stable a priority for these children and families is the child's participation in all aspects of life. This includes home, school, leisure, and community participation. Cameron et al.² demonstrate the potential of participation by highlighting the positive association between community participation, quality of life, and physical health, especially when the VPTs are more involved in activities (rather than observing). This is important work as of the six core International Classification of Functioning, Disability and Health domains, participation is one of the least researched,³ and even less so in relation to VPTs. The optimal environmental fit for children born preterm through to adulthood is not fully understood, and neither are their patterns of participation over time.

To date, little difference has been found in the participation levels of preschool children born VPT and at term. This contrasts significantly with adolescents and young adults born preterm who consistently show an adverse impact on participation relative to full-term peers.⁴ This discrepancy could be partly explained by participation in the early years being highly controlled and scaffolded by adult assistance. Caregivers have the potential to mask participation challenges by adapting the physical, social, or cognitive demands. This level of scaffolding can be accepted by the child, their peers, and the community as socially appropriate in these

early years. As children move into school systems there is an ever increasing expectation of autonomy, and an emphasis on more participation in structured and competitive sports that may highlight differences. However, regardless of the reason, our job as clinicians is to close the participation gap.

Therapeutic interventions internationally tend to focus on either making changes to the context (environment/society) or supporting changes in the child (motor, sensory, behavioural). It has been argued, and I agree, that focusing on either of these approaches in isolation will not be sufficient in maximizing participation outcomes.⁵ Children's participation is very complex and ever-changing. Multiple factors such as changes in a child's age and preferences, complexity of tasks, functional status, medical conditions, and environment all influence their participation. It may therefore be fair to say that sometimes we must chase participation. Supporting a child's participation may mean sometimes winning for periods of time (with the child enjoying being immersed in games with their peers) and other times we are left perplexed by how to get an 'in'.

I recently asked a school-aged child with a disability if they wished to participate in a community sport. They answered, 'No. I don't like it AND I'm not good at it.' The question I leave you with is, is this likely to be a true reflection of preference, or is it a result of progressive community experiences that unsuccessfully supported the child's efforts to participate? If the latter is the case, perhaps then the more accurate statement would be, 'I'm now not good at it AND so I don't like it.' We have a small window in childhood so let's make it count.

DATA AVAILABILITY STATEMENT

Not required.

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